

Testimony of Jill Hall, parent of DDS client  
Before the Public Health Committee  
In support of HB-5558: AN ACT CONCERNING SERVICE FOR PERSONAL WITH AUTISM  
SPECTRUM DISORDER  
MARCH 19, 2014

I wish to express my support for the addition of section 2 of the AN ACT CONCERNING SERVICE FOR PERSONAL WITH AUTISM SPECTRUM DISORDER, which states,

"the Commissioner of DDS in consultation with the Commissioner of DCF shall establish a pilot program for persons with developmental disabilities and personal who have been diagnosed with autism spectrum disorder who (1) require a high level of clinical services, (2) have been difficult for the Department of Developmental Service to place due to such person's behavioral needs, and (3) are on said department's emergency list or have been served primarily in a hospital setting or out-of state facilities."

This bill also states the "pilot program shall not serve more than 24 persons" and my first thought upon reading that fact was disbelief that there were actually 23 other families out there living the same nightmare that our families has been stuck in for the past nine years. My son is 23 years old, but developmentally much younger. He is highly volatile, impulsive, and can be a threat to himself or others. It is unsafe to leave him alone and we have experience extreme and traumatic events having him the family home. He has nowhere to go, and we have no hope in sight. Since the age of 5 he has been diagnosed with Pervasive Developmental Disability, which is among the Autism Spectrum Disorders, and his IQ test scores places him in the mildly mentally retarded category. He was a clear danger to himself as early as the age of 11. Somehow, we somehow managed to keep him safe for four (4) years. By the time he was 14 years old, containment had become impossible and by then I had also burned through any natural supports or state assisted community based services available to us. My son is friendly and likable, but he has hurt me, hurt himself and hurt others, and not always unintentionally. Ever since that prepubescent age, he has been served primarily in hospital settings and out-of state facilities, including Hampstead Hospital - New Hampshire, UMASS neuropsychiatric unit - Massachusetts, and KidsPeace Crisis Center, Pennsylvania, just to name a few. About a million miles of driving later, we just couldn't handle the separation anymore; it was proving very difficult for him who needed his family for love and protection, and for me who could no longer bare the distance and pain that comes with it. The last straw and final end to his out-of state placement's was a DDS placement in a 5-person group home in Massachusetts. There he

battered himself terribly and destroyed everything he was given, repeatedly (eyewear, clothing, household good, etc...). This overcrowded, under funded group home was clearly not what he needed, and as such, his stepfather and I insisted that he be returned to Connecticut, which unbelievably took 8 months for the Department to coordinate.

Given my son's high need for on-site clinical oversight and the challenging behaviors that include aggression, self-injury and massive property destruction, the **Department of Developmental Service** hasn't been able to place him each time they have tried (with one exception – that horrible MA CLA). We have been through the request for proposal (RFP) process for the development of CT based group home three times now, and have yet to find a placement. Twice the private sector grantees rescinded the contact because the level of need exceeded the budget allowed. Each time this gobbled up 8 – 18 months of time and all the energy and emotion you might imagine goes with that type of needless waiting. The other failed attempt at placement was a sole source contract request made by DDS South region to some hand selected DDS provider, who we met and who brought us hope for a future with some sense of normalization to it. But DDS didn't award the private sector agency the contract. What's worse, they never even told why us, but no doubt it was an issue of inadequate funding. About the time this current legislative session ends (May 2014) our family will have been waiting 5 year for some glimmer of hope about the provision of services for our son and young adults like him.

The development, implementation, and success of the pilot program described in this bill (HB-5558) is of utmost importance to families such as mine and our loved one who the Department of Developmental Services is currently ill-equipped to serve.

As strange as it sounds, I take some comfort knowing that I am not the only mother who has no control over the happenings in their disabled child's life, and that there are other families to join with who feels completely left to the devices of the Department.

Explaining any of this to autistic intellectually disabled son.

But none of this makes sense to my

At the time the current legislative session closes, for

I have a young adult who I see weekly and speak to daily. I have no control over the happenings in his life, and I am left completely to the devices of the Department, and yet, I am the only one accountable from this young man's point of view. He reminds every time I speak with him how much he needs my help – and now I need your help. I have said it before and I will say it again, closing all state facilities has been a mistake not yet fully realized, because there is a real need for self-containment morale therapy models of care for individuals with dual neurological/developmental/psychiatric conditions.